

SUMMARY OF ADVISORY COMMITTEE MEETING  
Virginia Early Hearing Detection and Intervention Program  
Virginia Department of Health  
June 9, 2006  
FINAL

The following persons attended the meeting of the Virginia Early Hearing Detection and Intervention (EHDI) Program Advisory Committee: Frank Aiello, Barbara Allen, Jeannine Beden, Nancy Bond, Jackie Busa, Mark Campano, Pat Dewey, Darlene Donnelly, Ruth Frierson, Ann Hughes, Jennifer Hutson, Claire Jacobson, Lou Lambert, Sue Lau, Jackie Meeks, Dan Montero, Stephanie Moody, Debbie Pfeiffer, Leslie Prince, Barry Strasnick, Beth Tolley, and Susan Ward.

**Announcements and Updates**

- The September meeting will be held at Children's Hospital, in Richmond. The December meeting will be held at the offices of the Virginia Hospital and Healthcare Association, in Glen Allen.
- Carol Wiegler, who was the representative from Virginia School for the Deaf and Blind (VSDB) in Staunton prior to her move to JMU, submitted her letter of resignation for both the Advisory Committee and the Workgroup.
- Dr. Dan Montero is a new member to the group. He represents the Virginia Association of Family Practice. He brings to this group an additional perspective as that of a parent.
- Lou Lambert is the new EHDI staff at Virginia Department of Health (VDH). She will be working with Ruth Frierson on tracking and follow up.
- Dr. Walter Nance was the featured speaker at the International EHDI Conference in Cuomo, Italy. His article entitled Newborn Hearing Screening-A Silent Revolution, coauthored with Dr. Cynthia Morton, was published in the May 18 edition of the New England Journal of Medicine.
- Frank Aiello reported that the American Academy of Pediatrics (AAP) is developing an algorithm for children who fail the language portion of their development screening. It will be integrated with recommendations from Bright Futures and the Joint Committee on Infant Hearing. AAP continues to identify ways to offer information and support to colleagues including a planned training for OBs, nurse practitioners, and midwives on the subject of persons with disabilities. The AAP also is collaborating with the Alexander Graham Bell Association and Health and Human Services to educate legislators.
- Jackie Meeks announced that the 2006 AG Bell Association International Conference would be held June 23-27, in Pittsburgh, PA.
- Claire Jacobson attended the International EHDI Conference and reported that for the most part other countries are years behind the United States in the early identification of hearing loss. Overall, all countries seem to be struggling with the same issues and problems.
- Ann Hughes reported on the training and education projects being conducted by the Partnership for People with Disabilities through contract with VDH. This work is supported by federal grant funds. Previously trained early intervention providers from 2004 and 2005 will receive a refresher course on the SKI-HI model of service provision; this is scheduled for late June. Sixteen early intervention providers have registered for the on line classes being offered through the Institute for Hard of Hearing and Deaf, National University, in California. A repeat of the teleconferences for primary medical care providers is being planned for August. Training for the new parent guides also will be handled under this contract.

### **National EHDI Conference-Parent Perspective**

- For the past three years, VDH has supported a parent to attend the national EHDI Conference. This year, Jennifer Hutson attended the conference, which was held in Washington, DC.
- Jennifer Hutson related her experiences as a parent of a child with hearing loss and shared her thoughts on the conference. She was overwhelmed at the new language and all the acronyms used when discussing EHDI. She felt it was a great experience and much information was shared during the sessions. Her favorite session was on Hands and Voices, a parent-driven organization that provides non biased information and support for families of children with hearing loss. She appreciated being able to attend.
- Other points made: parents need to be educated regarding how to deal with the fact that about 40% of children who are deaf will have some other type of disability, trained early intervention providers are still lacking in many areas, and it is important to involve persons who have hearing loss in EHDI conferences and activities in order to obtain their perspective.

### **Report from Virginia Department of Health**

- As of the end of April, the Virginia Hearing Aid Loan Bank has provided loaner aids or FM systems to 46 children. Twenty-two audiologists have participated. VDH recently arranged for a trade-in of ten of the FM systems - five each of Phonak and Oticon. Ten new Phonak hearing aids and 13 new Oticon aids were received in exchange. VDH will be able to support this bank using funds from the federal grant for the next two years, as long as the funds are available. By spring 2007, VDH will begin to explore support for the loan bank beyond the grant period.
- Claire Jacobson will take the lead in convening a Work Group to revise the audiology assessment protocols. Other audiologists from the Advisory Committee will serve on the Work Group.
- The second-year grant application was submitted to Health Resources and Services Administration on May 22. The second year begins September 1. The focus in year two will be to support the second follow-up position, maintain the hearing aid bank, continued training for audiologists and early intervention providers, travel to the National EHDI Conference, and establishment of the parent guide program.

### **Report from Work Group**

- Beth Tolley reported on the progress of the Work Group, formed in 2005 to address the needs of Virginia families with a newly diagnosed infant who is deaf or hard of hearing for timely, unbiased, and complete information regarding communication options and available resources. The group is working on the development of a Family Guide Program using the model of Guide By Your Side, a program that originated in Wisconsin. This program model is now being managed by Hands & Voices, a nationwide non-profit, parent-driven, parent/professional collaborative organization dedicated to supporting families and their children who are deaf or hard of hearing, as well as the professionals who serve them. The Family Guide will be a trained parent who will provide support and information to parents of children recently identified with hearing loss. Management of the program and the training will be handled under the contract with the Partnership for People with Disabilities at Virginia Commonwealth University. Training of both the guides and future trainers has been tentatively scheduled for October. Grant funding will be used for start-up, but the program will need a permanent funding source to continue. There are several parents who have expressed an interest in beginning a Hands & Voices chapter in Virginia.

### **Report from Surveillance and Evaluation Coordinator**

- Sue Lau reported on program data from 2003 through 2005 (birth years). The 2005 data are still preliminary; final numbers will be available in August. Progress has been made but more emphasis will now be placed on diagnosis before 3 months of age and intervention before 6 months of age.

- VDH is collaborating with the Centers for Disease Control and Prevention (CDC) on a program evaluation project that involves two surveys. One is a maternal exit survey that is being administered by four hospitals, and the other is a telephone survey of mothers regarding the hearing screening process. By the end of summer, the EHDI Program will be conducting a survey of parents of babies who have been diagnosed with hearing loss. Questions will focus on the follow-up process, including access to service issues, satisfaction with audiology services, and identifying gaps in services.

### **Report from Follow-Up Coordinator**

- Ruth Frierson reported that follow up activities will begin to focus on babies reported as transferred out of state and on children who fail both the initial and follow-up screening.
- The hospital brochures are now over six years old and need to be reworked and printed. New brochures are being developed that can be used in birthing hospitals, physician offices, and clinics, as well as for families of children not born in hospitals.
- Another brochure will be developed to address those babies who fail both the hospital and a follow-up screening.
- The scope of follow up is expanding to provide information to obstetric offices, birthing centers, and local health departments to make parents aware of newborn hearing screening process and the availability of the EHDI Program for information and referral if a hearing loss is identified.
- The National Center for Hearing Assessment and Management (NCHAM) distributed an informational packet to EHDI programs that targets primary medical care providers. The information was designed to inform them about EHDI issues and encourage routine hearing screening as part of routine pediatric care.
- The group divided into small groups to review the new brochure. The recommendations will be incorporated as appropriate.

### **Discussion**

- The group discussed attempts over the past three years by Senator Ticer and others to mandate insurance coverage for children's hearing aids. Points made were:
  - mandating benefits may actually help fewer people than are being serviced now.
  - there are many companies that would not be affected by a mandate.
  - employers should be encouraged to provide this coverage as part of their package
  - in some states children who are deaf are automatically eligible for Medicaid and can receive hearing aids.
  - Families and consumers are the best advocates for this effort.
- Some of the failure to identify congenital hearing loss before 3 months of age is caused by the fact that parents are unable to make appointments within the recommended time frames. A contributing factor is the shortage of audiologists and audiology facilities in certain areas.
- The group discussed the need to identify and recruit new members to the Advisory Committee from areas or groups not previously represented. Candidates include a deaf or hard of hearing consumer, a physician specializing in obstetrics, and a representative from the General Assembly. Members were encouraged to send the names and information on suggested members to Pat Dewey. By law, the Commissioner of Health must appoint all members of the Advisory Committee.
- Barry Strasnick reported that he is leading an effort to establish a foundation that would interact with all public and private entities to address the needs of families of children with hearing loss. The foundation could ultimately address issues from "cradle to grave." He requested that members of the group send suggestions and ideas to him.
- Leslie Prince stated that, from her perspective, the three critical areas are hearing aids, qualified sign language interpreters, and emergency preparedness and response. Debbie Pfeiffer stated that helping parents become good advocates also is important.

- Mark Campano suggested that the Together We Can deaf/blind project and VDH work together to assure that families of children with hearing loss have information about risk of vision loss and to identify children who have both hearing and vision loss. The EHDI Program does not currently collect this information; however, VACARES (Virginia's birth defect registry) does.
- Frank Aiello stated that recommendations for medical management include an ophthalmologic evaluation but that there is no way to determine whether those referrals are being made by the child's medical care provider. Barry Strasnick wondered how many children are receiving the other recommended medical evaluations.
- The group discussed how best to obtain this information from primary medical care providers as well as to educate them about recommended medical management. Barry Strasnick will draft a simple, one-page checklist to be distributed to the group for review and input. Frank Aiello suggested that the guidelines for medical management be included with the survey. Dan Montero suggested we also include contact information for Part C Early Intervention.
- Barry Strasnick expressed his concern that the EHDI Program cannot demonstrate false positive or false negative rates for newborn hearing screening.

### **Next Meeting**

The next meeting is scheduled for September 8, 2006. It will be held in the auditorium at Children's Hospital, located at 2824 Brook Road, in Richmond.